

General

Guideline Title

HIV disclosure to parents and consent to HIV treatment among adolescents.

Bibliographic Source(s)

New York State Department of Health. HIV disclosure to parents and consent to HIV treatment among adolescents. New York (NY): New York State Department of Health; 2012 Nov. 3 p. [2 references]

Guideline Status

This is the current release of the guideline.

Recommendations

Major Recommendations

The quality of evidence (I-III) and strength of recommendation (A-C) are defined at the end of the "Major Recommendations" field.

Adolescent Consent according to New York State Law

Whenever possible, clinicians should obtain parental or legal guardian consent for human immunodeficiency virus (HIV)-related treatment for adolescents under 18 years of age who may be unable to consent to care according to New York State law.

Clinicians should be versed in New York State laws regarding consent and confidentiality for adolescents under 18 years of age and should educate their HIV-infected adolescent patients about these laws. (AIII)

Clinicians should refer to their institutional policy or consult with the institution's legal department regarding adolescents under 18 years of age who refuse to disclose their HIV status to their parents or legal guardians and may be unable to consent to care according to New York State law.

Minors Who Are Eligible to Consent to HIV Treatment

Clinicians should encourage adolescents who consent to their own care to identify an adult who can provide support.

Minors Who Are Ineligible to Consent to HIV Treatment

Clinicians should clearly document discussions regarding consent and disclosure of HIV status to parents and legal guardians in the HIV-infected adolescent's medical record. (AIII)

Medical Management and Engagement in the Process of Disclosure

Key Points:

- Adolescent patients may be at risk for abuse if they disclose their HIV status. Appropriate referrals and assistance should be offered to patients reporting such risks.
- Discussions about disclosure and possible risks to the adolescent should be documented in the medical record.
- Coordination with insurance companies is necessary to ensure that confidentiality is managed according to patients' wishes.

The [New York State Department of Health \(NYSDOH\) AIDS Institute's Dear Colleague Letter](#) provides information about minors' confidentiality rights with insurance companies.

Definitions:

Quality of Evidence for Recommendation

- I. One or more randomized trials with clinical outcomes and/or validated laboratory endpoints
- II. One or more well-designed, non-randomized trials or observational cohort studies with long-term clinical outcomes
- III. Expert opinion

Strength of Recommendation

- A. Strong recommendation for the statement
- B. Moderate recommendation for the statement
- C. Optional recommendation

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

Human immunodeficiency virus (HIV) infection

Guideline Category

Counseling

Clinical Specialty

Allergy and Immunology

Family Practice

Infectious Diseases

Internal Medicine

Pediatrics

Intended Users

Advanced Practice Nurses

Health Care Providers

Nurses

Physician Assistants

Physicians

Public Health Departments

Guideline Objective(s)

To provide guidance on how to engage youth in the process of disclosing their human immunodeficiency virus (HIV) status to parents or legal guardians and how to medically manage these patients while resolving issues of consent

Target Population

Human immunodeficiency virus (HIV)-infected adolescents under 18 years of age

Interventions and Practices Considered

1. Obtaining parental or legal guardian consent for human immunodeficiency virus (HIV)-related treatment for adolescents under 18 years of age who may be unable to consent to care according to New York State law
2. Educating HIV-infected adolescent patients about consent laws
3. Encouraging adolescents who consent to their own care to identify an adult who can provide support
4. Documenting discussions regarding consent and disclosure of HIV status in the patient's medical record

Major Outcomes Considered

Providing appropriate care to human immunodeficiency virus (HIV)-infected minors that minimizes HIV disease progression

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Description of Methods Used to Collect/Select the Evidence

Medline was searched through September 2012, using appropriate key words. There was no time framework to exclude results, because of the specificity of the topic. Because there are no case controlled studies on this topic, case reports and practitioner experience were also consulted. Much of this guideline is based on requirements of New York State Public Health Law Sections 2504 and 2782(4)(e).

Number of Source Documents

Not stated

Methods Used to Assess the Quality and Strength of the Evidence

Expert Consensus (Committee)

Weighting According to a Rating Scheme (Scheme Given)

Rating Scheme for the Strength of the Evidence

Quality of Evidence for Recommendation

- I. One or more randomized trials with clinical outcomes and/or validated laboratory endpoints
- II. One or more well-designed, non-randomized trials or observational cohort studies with long-term clinical outcomes
- III. Expert opinion

Methods Used to Analyze the Evidence

Review

Description of the Methods Used to Analyze the Evidence

Not stated

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

AIDS Institute clinical guidelines are developed by distinguished committees of clinicians and others with extensive experience providing care to people with HIV infection. Committees* meet regularly to assess current recommendations and to write and update guidelines in accordance with newly emerging clinical and research developments.

The Committees* rely on evidence to the extent possible in formulating recommendations. When data from randomized clinical trials are not available, Committees rely on developing guidelines based on consensus, balancing the use of new information with sound clinical judgment that results in recommendations that are in the best interest of patients.

* Current committees include:

- Medical Care Criteria Committee
- Committee for the Care of Children and Adolescents with HIV Infection
- Dental Standards of Care Committee
- Mental Health Guidelines Committee
- Committee for the Care of Women with HIV Infection
- Committee for the Care of Substance Users with HIV Infection
- Physicians' Prevention Advisory Committee
- Pharmacy Advisory Committee

Rating Scheme for the Strength of the Recommendations

Strength of Recommendation

- A. Strong recommendation for the statement
- B. Moderate recommendation for the statement

C. Optional recommendation

Cost Analysis

A formal cost analysis was not performed and published cost analyses were not reviewed.

Method of Guideline Validation

External Peer Review

Description of Method of Guideline Validation

All guidelines developed by the Committee are externally peer reviewed by at least two experts in that particular area of patient care, which ensures depth and quality of the guidelines.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The type of supporting evidence is identified and graded for selected recommendations (see the "Major Recommendations" field).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

Appropriate process of disclosing human immunodeficiency virus (HIV) status to parents or legal guardians of adolescents and obtaining their consent to medical treatment

Potential Harms

Adolescent patients may be at risk for abuse if they disclose their human immunodeficiency virus (HIV) status. Appropriate referrals and assistance should be offered to patients reporting such risks.

Qualifying Statements

Qualifying Statements

When formulating guidelines for a disease as complex and fluid as human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), it is impossible to anticipate every scenario. It is expected that in specific situations, there will be valid exceptions to the approaches offered in these guidelines and sound reason to deviate from the recommendations provided within.

Implementation of the Guideline

Description of Implementation Strategy

The AIDS Institute's Office of the Medical Director directly oversees the development, publication, dissemination and implementation of clinical practice guidelines, in collaboration with The Johns Hopkins University, Division of Infectious Diseases. These guidelines address the medical management of adults, adolescents and children with human immunodeficiency virus (HIV) infection; primary and secondary prevention in medical settings; and include informational brochures for care providers and the public.

Guidelines Dissemination

Guidelines are disseminated to clinicians, support service providers and consumers through mass mailings and numerous AIDS Institute-sponsored educational programs. Distribution methods include the HIV Clinical Resource website, the Clinical Education Initiative (CEI), the AIDS Educational Training Centers (AETC) and the HIV/AIDS Materials Initiative. Printed copies of clinical guidelines are available for order from the New York State Department of Health (NYSDOH) Distribution Center for providers who lack internet access.

Guidelines Implementation

The HIV Clinical Guidelines Program works with other programs in the AIDS Institute to promote adoption of guidelines. Clinicians, for example, are targeted through the CEI and the AETC. The CEI provides tailored educational programming on site for health care providers on important topics in HIV care, including those addressed by the HIV Clinical Guidelines Program. The AETC provides conferences, grand rounds and other programs that cover topics contained in AIDS Institute guidelines.

Support service providers are targeted through the HIV Education and Training initiative which provides training on important HIV topics to non-physician health and human services providers. Education is carried out across the State as well as through video conferencing and audio conferencing.

The HIV Clinical Guidelines Program also works in a coordinated manner with the HIV Quality of Care Program to promote implementation of HIV guidelines in New York State. By developing quality indicators based on the guidelines, the AIDS Institute has created a mechanism for measurement of performance that allows providers and consumers to know to what extent specific guidelines have been implemented.

Finally, best practices booklets are developed through the HIV Clinical Guidelines Program. These contain practical solutions to common problems related to access, delivery or coordination of care, in an effort to ensure that HIV guidelines are implemented and that patients receive the highest level of HIV care possible.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Living with Illness

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

New York State Department of Health. HIV disclosure to parents and consent to HIV treatment among adolescents. New York (NY): New York State Department of Health; 2012 Nov. 3 p. [2 references]

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2012 Nov

Guideline Developer(s)

New York State Department of Health - State/Local Government Agency [U.S.]

Source(s) of Funding

New York State Department of Health

Guideline Committee

Adolescents with HIV Infection Subcommittee

Committee for the Care of Children and Adolescents with HIV Infection

Composition of Group That Authored the Guideline

Adolescents with HIV Infection Subcommittee

Members: Aracelis D Fernández, MD, FAAP, Children's Hospital at Montefiore, Bronx, New York; Natalie M Neu, MD, MPH, Columbia University, New York, New York; Anthony Vavasis, MD, Callen-Lorde Community Health Center, New York, New York; Barbara L Warren, BSN, MPH, PNP, New York State Department of Health AIDS Institute, Albany, New York

AIDS Institute Staff Liaison: Jeffrey M Birnbaum, MD, MPH, SUNY Downstate Medical Center, Brooklyn, New York

AIDS Institute Staff Physician: Charles J Gonzalez, MD, New York State Department of Health AIDS Institute, New York, New York

Principal Contributor: Jeffrey M Birnbaum, MD, MPH, SUNY Downstate Medical Center, Brooklyn

Peer Reviewers: John B Steever, MD, Mount Sinai Adolescent Health Center, New York; Donna Futterman, MD, Children's Hospital at Montefiore Medical Center, Albert Einstein College of Medicine, Bronx

Committee for the Care of Children and Adolescents with HIV Infection

Chair: Geoffrey A Weinberg, MD, University of Rochester School of Medicine and Dentistry, Rochester, New York

Vice-Chair: Roberto Posada, MD, Mount Sinai Hospital, New York, New York

Members: Jacobo Abadi, MD, Jacobi Medical Center, Bronx, New York; Aracelis D Fernandez, MD, FAAP, Children's Hospital at Montefiore, Bronx, New York; Marc D Foca, MD, Children's Hospital of New York, New York, New York; Natalie M Neu, MD, Columbia University, New York, New York; Warren Yiu Kee Ng, MD, NewYork-Presbyterian Hospital, New York, New York; Joseph A Puccio, MD, FAAP, Stony Brook University Hospital, Stony Brook, New York; Michael G Rosenberg, MD, PhD, Jacobi Medical Center, Bronx, New York; Pauline A Thomas, MD, New Jersey Medical School, Newark, New Jersey; Anthony Vavasis, MD, Callen-Lorde Community Health Center, New York, New York; Barbara L Warren, BSN, MPH, PNP, New York State Department of Health AIDS Institute, Albany, New York

New York City Department of Health and Mental Hygiene Liaison: Vicki B Peters, MD, New York City Department of Health and Mental Hygiene, Long Island City, New York

Financial Disclosures/Conflicts of Interest

Not stated

Guideline Status

This is the current release of the guideline.

Guideline Availability

Electronic copies: Available from the [New York State Department of Health AIDS Institute Web site](#) .

Availability of Companion Documents

None available

Patient Resources

None available

NGC Status

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